HHS Public Access

Author manuscript

Eur J Cancer Care (Engl). Author manuscript; available in PMC 2019 January 01.

Published in final edited form as:

Eur J Cancer Care (Engl). 2018 January ; 27(1): . doi:10.1111/ecc.12540.

Factors Underlying Metastatic Breast Cancer Patients' Perceptions of Symptom Importance: A Qualitative Analysis

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Abstract

The symptom literature in cancer has primarily examined symptom severity, frequency, and distress. Assessing cancer patients' perceptions of symptom importance—how important it is for them to see improvement in a symptom following an intervention—and factors influencing these judgments would also inform patient-centred care, but this analysis has not been undertaken. This qualitative study aimed to identify factors underlying perceptions of symptom importance among 25 symptomatic metastatic breast cancer (MBC) patients. Participants were recruited from a cancer centre in the Midwestern USA. Semi-structured interviews focused on patients' rationale for considering common symptoms (i.e., anxiety, sadness, sleep problems, pain, or fatigue) to be important. Thematic analyses revealed five interrelated factors underlying MBC patients' perceptions of symptom importance: activity restriction, concentration difficulties, exacerbation of other physical symptoms, symptom-related long-term health concerns, and negative impact on their relationships with others. Patients most frequently stated that a physical or psychological symptom was important because of the resulting activity restriction. Additionally, some patients considered pain to be important because it signalled potential long-term health concerns, such as worsening metastatic disease. Findings suggest that clinicians should take into account MBC patients' perceptions of symptom importance and factors underlying these judgments when making shared treatment decisions.

Keywords

metastatic breast cancer; symptoms; psychological; pain; fatigue; anxiety

INTRODUCTION

Breast cancer is the leading cause of cancer deaths in women worldwide, accounting for 521,900 deaths in 2012 alone (American Cancer Society, 2015). Symptoms are highly prevalent and undertreated in metastatic breast cancer (MBC) patients and are a major source of suffering, impairment, and disability (Aranda et al., 2005; Cleeland et al., 2014; Given et al., 2007; Lam et al., 2013; Low & Stanton, 2015; Mosher & Duhamel, 2012; Willis et al., 2015). The most prevalent, persistent, and disabling symptoms in this population include depression, anxiety, sleep disturbance, pain, and fatigue (Aranda et al., 2005; Grabsch et al., 2006; Kissane et al., 2004; Koopman et al., 2002; Palesh et al., 2007). Research suggests that 36% of MBC patients have depression, anxiety, or both (Grabsch et al., 2006). Worsening depression has been associated with negative changes in sleep in MBC patients (Palesh et al., 2007), with over 60% reporting one or more types of sleep disturbance (Koopman et al., 2002). Sleep problems often co-occur with pain and fatigue, with over half of MBC patients reporting significant levels of these symptoms (Aranda et al., 2005; Cleeland et al., 2014; McGuire & Sheidler, 1992).

Research on symptoms in MBC and other cancer patients has primarily examined symptom severity, frequency, and distress (Fan et al., 2007; Willis et al., 2015). A notable gap in this research is assessing which symptoms are most important from the patient's perspective. For example, a patient who has daily pain but only occasional fatigue might experience the fatigue as more bothersome and debilitating, leading the patient to place greater importance on alleviating fatigue than pain. Understanding patients' priorities with respect to symptom improvement is critical for the provision of patient-centred care, which takes into account patients' needs, values, and preferences, and some evidence suggests that it improves health care quality, disease outcomes, and patient satisfaction while reducing health care costs (Dwamena et al., 2012; Epstein et al., 2010).

Although perceptions of symptom importance have not been studied in cancer patients, these perceptions have been assessed in patients with chronic pain conditions (Robinson et al., 2005). Studies have found that not all patients prioritize improvement in the same symptoms; some patients were most interested in pain reduction, whereas others placed greater emphasis on improvement of other symptoms, such as fatigue or emotional distress (Robinson et al., 2005; Yi et al., 2014; Zeppieri et al., 2012). Not only do patients differ in the specific symptoms they consider most important, they also differ in the overall number of symptoms they prioritize for improvement. Such differences in number of prioritized symptoms may be related to important outcomes. For example, patients with chronic pain who rate all symptoms as highly important have been found to experience greater anxiety and depressive symptoms (Yi et al., 2014; Zeppieri et al., 2012).

Given their considerable symptom burden, similar findings may be expected in symptomatic MBC patient samples. However, some of the factors driving perceptions of symptom importance may be unique to MBC patients. For example, some MBC patients may view pain as a treatment priority because of its association with disease metastasis. Understanding MBC patients' symptom priorities will enable the design of patient-centred interventions that promote shared treatment decision-making between patients and providers. Therefore,

the goal of this qualitative study was to identify factors underlying symptomatic MBC patients' perceptions of the importance of seeing improvement in symptoms following an intervention. Our analysis focused on the importance of reducing anxiety, sadness, sleep problems, pain, and fatigue because they are among the most common and disabling symptoms in this population (Aranda et al., 2005; Grabsch et al., 2006; Palesh et al., 2007; Willis et al., 2015).

METHODS

Recruitment

Women with stage IV breast cancer were recruited from an academic cancer centre in Indianapolis, Indiana between May and August 2015. The cancer centre's institutional review board approved all study procedures. Following oncologist approval, letters inviting study participation and consent forms were mailed to patients. Then research assistants called patients to screen them for eligibility and complete the informed consent process. Eligible patients were at least 18 years of age and fluent in English. Patients were excluded from study participation if they made three or more errors on a validated 6-item cognitive screener (Callahan et al., 2002). At the time of enrolment, participants received a brochure providing contact information for mental health services at the cancer centre.

Data collection

Consenting patients completed a standardized telephone assessment of their physical and psychological symptoms and perceptions of symptom importance. Patients who endorsed a usual level of 4 or higher on a 0 to 10 scale for anxiety, sadness, sleep problems, pain, or fatigue on the Patient Centered Outcomes Questionnaire (PCOQ; Robinson et al., 2005) were invited to participate in an in-depth, semi-structured telephone interview. This interview explored factors underlying patients' perceptions of symptom importance (i.e., the degree to which symptoms were viewed as treatment priorities).

Interviews were conducted within 3 weeks of the standardized assessment by a female doctoral student in clinical psychology who had experience conducting qualitative interviews with cancer populations. Interviews ranged from 25 to 55 minutes and were digitally recorded. First, the interviewer selected the symptom (i.e., anxiety, sadness, sleep problems, pain, or fatigue) with the highest importance rating and asked the patient to describe her thoughts when rating the symptom's importance. If multiple symptoms had the highest importance rating, then the patient selected one of these symptoms to begin the interview. Subsequently, the patient was asked to indicate how the symptom affected her life. The interviewer asked follow-up questions to obtain rich information about factors underlying perceived symptom importance. Then the interviewer asked the same set of questions regarding the symptom with the second highest importance rating. Again, participants selected one symptom for the interview if multiple symptoms met this criterion. Patients received a $50 gift card for participating in the interview.

Patients reported their demographic information during the initial assessment. Patients' medical information (i.e., date of diagnosis and treatments received) was obtained from medical records.

Qualitative data analysis

Interviews were transcribed verbatim and imported into Atlas.ti for thematic analysis (Braun & Clarke, 2006). This method of qualitative analysis involves identifying, analysing, and reporting patterns or themes across a data set. We conducted an inductive thematic analysis rather than a theoretical one because the study was descriptive and exploratory (Braun & Clarke, 2006). A clinical psychologist who specializes in psycho-oncology and a radiation therapist with extensive clinical research experience read all transcripts and generated initial codes. The codes were refined as the researchers independently coded the transcripts in Atlas.ti and met regularly (i.e., after the first two transcripts and following every four transcripts thereafter) to review the codes and resolve differences in coding for each transcript. Then the researchers organized coded text into broader themes capturing the experiences and perceptions of participants, and then checked these interpretations against data across transcripts to ensure that the themes were internally consistent and distinct from one another.

RESULTS

Participant characteristics

Of the 107 MBC patients who received mailed information about this study, 85 (79%) completed the screening assessment, 12 (11%) could not be reached via phone, and 10 (9%) refused study participation. Following screening, two patients were found to be ineligible, and 83 patients were eligible and consented to participate.

Eighty patients (96%) completed the standardized phone assessment. Patients who had a usual level of 4 or higher on a 0 to 10 scale for anxiety, sadness, sleep problems, pain, or fatigue on the PCOQ (Robinson et al., 2005) were invited to participate in the qualitative interview. After 25 patients had completed the interview, the research team determined that thematic saturation had been reached. Saturation is the point at which no new narrative content codes are observed in the data, and further interviews are not expected to change the content codes or interpretation of the data.

Table 1 shows demographic and medical characteristics of the sample as well as means and standard deviations for severity and importance of the five symptoms. Patients were, on average, 54 years old, married, Caucasian, and college-educated (mean = 15 years of education). Patients were, on average, 2 years from a stage IV breast cancer diagnosis. On average, patients experienced mild levels of anxiety and sadness and moderate levels of sleep problems, pain, and fatigue. The average importance ratings for sleep problems, pain, and fatigue were slightly higher than those for anxiety and sadness (8 vs. 6, respectively, on a 0 to 10 scale).

Findings

Our thematic analysis identified five sets of interrelated factors underlying MBC patients' perceptions of symptom importance: activity restriction, concentration difficulties, exacerbation of other physical symptoms, symptom-related long-term health concerns, and negative impact on their relationships with others. Each of these factors is described below.

Activity restriction—The majority of patients rated symptoms as important because they restricted their social, recreational, or work-related activities. More patients described physical symptoms (i.e., sleep problems, pain, or fatigue) as restricting their activities more than psychological symptoms (i.e., anxiety or sadness). One patient noted her disengagement from valued activities when experiencing severe pain:

> I used to be extremely active so obviously cancer changes you . . . when the pain is really bad then I can't work in the garden. I can't take my grandbabies out on the bike. I can't power walk. I can't play tennis. I can't do the things that are just me . . . I'm notorious for a clean home so the pain levels definitely can hinder my cleaning, my cooking.

Another patient described how severe fatigue had restricted her activities:

> I can't do all the things I like to do normally . . . . Doing things for the kids or even just going to a concert is a big ordeal. To go eat in a restaurant --I don't even like doing that anymore because I get too tired of waiting . . . So being tired doesn't allow me to do any of the things I normally do. I mean I really sit in a chair all day. That's not really what I like to be doing.

Psychological symptoms were also found to be restrictive. One patient characterized her anxiety as an "overwhelming feeling" that resulted in social withdrawal:

> If I'm feeling really anxious I don't feel like going out of the house. I prefer to just stay home.

Concentration difficulties—Other patients perceived sleep problems, pain, or fatigue as important because of their negative effects on concentration. As one patient with severe fatigue stated:

> My dad just asked me yesterday what I was reading. I said I don't have the attention span to read books anymore. I think it's better if I just read news articles instead because I just fall asleep.

Although patients did not associate sadness with concentration deficits, several patients described how anxiety had produced these deficits. As one patient stated:

> Anxiety has dominated my life. Anxiety about the cancer and all aspects of treatment or side effects, or . . . my life span. All those things have controlled my thoughts and it distracts me from enjoying my day, or enjoying my life . . . when I get distracted with my thoughts, I don't hear what other people are saying. It's hard to hold on to conversations. It's hard interacting with other people and . . . interacting with what's around me, things I enjoy doing.

Exacerbation of other physical symptoms—Some patients viewed sleep problems and pain as treatment priorities because they exacerbated other symptoms. One patient noted that “pain interferes with sleep, which then causes fatigue.” Another patient found that severe pain led to unwanted weight loss:

> I love to cook. I cook from scratch. When I’m hurting real bad I can’t. And if I don’t cook, I’m not eating. If I’m not eating, I’m losing weight.

Conversely, fatigue, anxiety, and sadness were not described as precipitants of physical symptoms.

Symptom-related long-term health concerns—Some patients were concerned about the long-term health implications of sleep problems, pain, or fatigue when rating them as treatment priorities. For example, a few patients perceived pain as a sign that the cancer might be metastasizing. As one patient stated:

> In the affected area where the breast cancer is located, it concerns me as to whether it [the pain] is being contained in that same spot, or if it’s moving on to another area . . . Any other pain does not bother me; I think the cancer is one pain that I’m worrisome with.

Other patients were concerned that they would develop a chronic pain condition that would be poorly managed:

> The main thing about the pain I’ve experienced so far is the stress level and fear factor of this being the beginning of a pain that won’t go away and that won’t be controlled. So it’s more like uh-oh, is this it? Is this the one that’s never going to go away? So it increases stress and anxiety thinking what if this is here forever.

Another health concern was the impact of sleep disturbance on bodily function. One patient stated:

> It’s really important to have a good sleep pattern in order for your body to sustain itself and to help itself heal.

Negative impact on relationships with others—Lastly, some patients prioritized symptoms which were thought to negatively impact their relationships with others. For example, several patients noted their increased irritability when experiencing sleep problems or pain. One patient described how her pain affected her parenting:

> I have two young children, and I get very irritated when I’m in severe pain, so I tend to not have any patience.

The negative effects of sadness and anxiety on social demeanour were also discussed. One patient noted her social disengagement that accompanied sadness:

> It was difficult to really listen--enjoy other people and everyday things because all I could think about was my cancer and how sad it made me and I just didn’t feel--people would be talking about their lives and what’s going on, but I just felt like I was on the outside, not participating.

DISCUSSION

This study provides rich, descriptive information on factors driving the perceived importance of reducing specific symptoms in a symptomatic advanced cancer patient sample. MBC patients with at least one moderate to severe symptom (i.e., anxiety, sadness, sleep problems, pain, or fatigue) were asked to share the thoughts they had while determining symptom treatment priorities. The most common reason for symptom importance was its detrimental impact on activities. Impairments in daily activities and work productivity are highly prevalent in MBC patients and are associated with increased symptom burden (Cleeland et al., 2014; Low & Stanton, 2015). Moreover, research suggests that activity disruption is a major source of reduced enjoyment of life among MBC patients (Low & Stanton, 2015). The present findings connect this work to the clinical care setting by suggesting that MBC patients prioritize the treatment of symptoms that interfere with valued activities.

Some patients noted the long-term health implications of symptoms when asked to discuss their importance. For example, several patients viewed pain as a treatment priority due to its potential association with progressive metastatic disease. Fear of metastases is a common concern among MBC and other advanced cancer patients (Aranda et al., 2005; Voogt et al., 2005), and the present results suggest that this fear may lead some MBC patients to place a greater emphasis on pain reduction. Other patients prioritized pain reduction due to concern that they would develop a chronic, poorly controlled pain condition. Finally, some patients believed that a lack of sleep would impede healing processes and, therefore, rated sleep disruption as particularly important.

In addition to concerns about the downstream health effects of symptoms and their effect on activities, social factors appeared to influence MBC patients' prioritization of physical and psychological symptoms. Specifically, some patients noted their increased irritability or poor listening skills during conversations with close others when symptomatic. In a prior survey, concerns about loved ones were among the most common psychological needs of MBC patients (Aranda et al., 2005), and our findings suggest that the desire to maintain a positive social demeanour may underlie patients' emphasis on managing certain symptoms.

Other reasons that symptoms were viewed as treatment priorities included their negative effects on concentration. Although few studies have examined cognitive functioning in MBC patients (Aranda et al., 2005; Bender et al., 2005; Mayer, 2010), preliminary evidence suggests that concentration difficulties are associated with greater fatigue and other symptoms in this population (Bender et al., 2005). Additionally, in the current study, some patients considered pain or sleep disturbance to be treatment priorities because of their compounding effect on other symptoms (e.g., weight loss, fatigue). The detrimental impact of symptom co-occurrence on functional status and quality of life has been documented in patients with various cancers (Fan et al., 2007; Given et al., 2007). Thus, it is not surprising that MBC patients prioritized the treatment of symptoms that appeared to exacerbate other symptoms.

Limitations of the current study and directions for future research warrant mention. The sample primarily consisted of college-educated Caucasian patients. Further research is

needed to determine the transferability of study findings to diverse socioeconomic and ethnic groups. Additionally, this study focused on five of the most common and distressing symptoms for MBC patients; identifying factors underlying judgments of symptom importance for other symptoms (e.g., nausea, lymphedema) would expand the current analysis. Finally, longitudinal research would allow us to gain a better understanding of factors driving judgments of symptom importance at difference phases of the disease trajectory (e.g., diagnosis, treatment, and end-of-life).

Findings have a number of implications for intervention research and clinical practice with MBC patients. First, findings suggest that clinicians should assess the impact of specific symptoms on daily activities and functioning when determining treatment priorities. Additionally, the meaning of symptoms from the patient's perspective should be assessed. This information would inform patient-centred approaches to symptom-related education and treatment. For example, patients who interpret pain as a sign of disease metastases and therefore prioritize pain management might benefit from cognitive-behavioural approaches that gently challenge these beliefs. Other patients may prioritize symptoms that interfere with valued activities. These patients may benefit from Acceptance and Commitment therapy (ACT), which encourages a more flexible and meaningful way of living that is not governed by symptom intensity (Hulbert-Williams et al., 2015). Finally, results suggest that clinicians should assess MBC patients' perceptions of symptom importance and factors underlying these perceptions—not just symptom severity and frequency. For example, a checklist to rank symptoms in order of importance may facilitate shared treatment decision-making between the patient and provider. Given the high symptom burden of MBC patients, identifying their priorities for symptom improvement and beliefs underlying these priorities may optimize health care quality and their satisfaction and engagement in health care.

Acknowledgments

This study was supported by a grant from the Walther Cancer Foundation. Catherine Mosher was supported by K07CA168883 and K05CA175048 from the National Cancer Institute. Shelley Johns was supported by K05CA175048 from the National Cancer Institute. The authors would like to thank the study participants and the breast oncology team at the Indiana University Simon Cancer Center.

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Table 1

Sample characteristics ($N = 25$)

Characteristic	*n* (%)	Mean (SD)	Range
Age, years		54 (11)	33 to 69
Race			
Caucasian	22 (88%)		
African American	2 (8%)		
Other	1 (4%)		
Education, years		15 (2)	12 to 19
Employment status			
Employed	4 (16%)		
Not employed	21 (84%)		
Marital status			
Married or marriage equivalent	13 (52%)		
Not married	12 (48%)		
Time since diagnosis of Stage IV breast cancer, years		2 (2)	0 to 7
Type of breast cancer treatment			
Mastectomy	18 (72%)		
Lumpectomy	5 (20%)		
Chemotherapy	22 (88%)		
Radiation	14 (56%)		
Targeted therapy	14 (56%)		
Hormonal therapy	18 (72%)		
Usual symptom levels[a]			
Anxiety		2 (2)	0 to 8
Sadness		2 (3)	0 to 8
Sleep problems		4 (2)	0 to 7
Pain		3 (3)	0 to 9
Fatigue		5 (2)	2 to 10
Perceived symptom importance[b]			
Anxiety		6 (4)	0 to 10
Sadness		6 (4)	0 to 10
Sleep problems		8 (3)	0 to 10
Pain		8 (3)	0 to 10
Fatigue		8 (2)	3 to 10

SD = standard deviation.

[a] Each symptom was rated on a scale from 0 (*none*) to 10 (*worst imaginable*).

[b] Each symptom was rated on a scale from 0 (*not at all important*) to 10 (*most important*).